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STRESS AMONG CAREGIVERS OF INDIVIDUALS
WITH SPECIAL NEEDS

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Ida Sierra Benavides

June 2019

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ABSTRACT

This research study focuses on gathering data on stress among caregivers caring for an individual with special needs. The participants selected were from three agencies in Southern California. Once the participants were selected, an interview was conducted using an audio recording device to gather and analyze the data collected. I dictated the responses provided during the interview if the participants did not wish to be recorded. All participants received a \$5 Starbucks gift card for their participation. This study was conducted to inform clinicians and any reader on the daily struggles and challenges caregivers face by caring for individuals with a disability. This study had a sample size of eight participants. Themes that were used were service utilization, social support systems, mental and physical health and self-care. Social workers working with individuals who care for individuals with special needs should be knowledgeable in coping strategies.

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I would like to thank my husband for giving me the support throughout this journey and for taking care of our children and home while I was busy doing schoolwork. Without this, it would not have been possible for me to complete my degree. I love you and appreciate all that you do and did for me. Words cannot express the gratitude I have for you and our children. I would also like to thank my research advisor Dr. Carolyn McAllister for providing guidance and support through this research. Lastly, I would like to thank my family who understood that I could not go out because I was busy working on assignments. Thank you for all your understanding.

DEDICATION

I dedicate this study to first and foremost my Lord and Savior Jesus Christ. Through prayer and guidance, I would not have been able to complete this study. Next, I want to dedicate this study to my children who inspired me to continue going to school and who were patient enough when mommy was busy. Lastly, this study would not have been possible if it were not for my daughter Bria. It has not been easy caring for a child with special needs, but your smile drives me to be the best in everything. I love you my princess.

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CHAPTER ONE

INTRODUCTION

Introduction

The introduction chapter discusses the research focus, the paradigm used to conduct the research, an overview of the research literature, and the contribution the study will have on micro and macro social work practice. This research project is based on a post-positivist perspective and the issues addressed will be based on stress among caregivers of individuals with special needs. This project will explore how caregivers cope and prevent stress from getting out of control from the day-to-day needs it takes to care for a special needs individual. Social workers can contribute by providing workshops, resources, and other community-based activities specifically geared toward parents of special needs individuals.

Caregivers who care for an individual with special needs require much of their time and attention. Social workers help their clients with many issues related to mental health concerns including stress, anxiety, and depression. One of the main reasons that individuals see a clinician is because of stress in their life, which in turn can lead to chronic anxiety and depression if left untreated. Clinicians should be aware that caring for a person with special needs could be a challenge for workers and they must be knowledgeable in all areas of practice in order to help their clients manage stress effectively. Clinicians who see

individuals related to stress should have some knowledge of the hard work it takes caring for an individual with special needs.

This project was conducted in agencies that serves families who care for individuals with special needs that helped the researcher identify emotional stressors, its impact on caring for a special needs individual and the levels of stress it causes. The research project focuses on gaining insight on many individuals seek intervention when feeling stressed because of these stressors. This project identified if caregivers have any assistance that provides respite care in order to care for one self in order to be able to care for their loved ones.

Definition of Special Needs

Special needs individuals can be defined as those having a neurological or physical impairment, which requires complete care in activities of daily living. Conditions such as autism, cerebral palsy, Down syndrome, cancer, and cerebral vascular accident are among the classified group of severe illnesses that causes immense stress among caregivers depending on the severity of the condition (Hack et al., 2005). The more severe the condition, the more the caregiver is exposed to high levels of stress (Smith, Oliver, and Innocenti, 2001) and burnout can occur along with other conditions such as depression and anxiety.

McPherson, et al. (1998) defines special needs children as...

Children with special healthcare needs are those who have or are at increased risk of chronic physical, developmental, behavioral, or emotional

condition and who require health and related services of a type or amount beyond that required by children generally (p.138).

However, having special needs is not only limited to children, but adults who were born with a physical, developmental, or emotional impairment or experienced an illness or accident that caused such impairments. Age related diseases and impairments are on the rise as elderly adults have a higher life expectancy. Diseases such as cerebral vascular accidents, severe dementia, and Alzheimer's disease are often diagnosed in the elderly population, have an impact both physically and intellectually, and cause high levels of stress among caregivers (Haley, Levine, Brown, & Bartolucci, 1987).

Evenhuis, Henderson, Beange, Lennox, and Chicoine, (2001) point out that the risk of chronic diseases acquired during adulthood is often associated with older-age mobility and functional impairments and that hereditary and environmental predispositions are present in older persons. The burden of long-term care falls on families, and families must deal with various combinations of physical, emotional, and cognitive disability in individuals who have acquired limitations due to conditions such as a stroke (Hartke, King, Heinemann, & Semik, 2006).

Other ways people become physically and mentally disabled are due to accidents and conditions that impair a person's quality of life. For example, automobile or any head trauma accident, amyotrophic lateral sclerosis (ALS), and multiple sclerosis are some conditions that cause impairment and debilitate a

person's life. An external mechanical force leading to loss of consciousness and coma causes traumatic brain injuries. These are caused by accidents that affect a person's cognition, emotional, and social functions (Verhaeghe, Defloor, & Grypdonck, 2005). These conditions cause stress on the individual who has it as well as those impacted by it because they have to adjust their life back to normalcy. What they defined normal is now shattered by having to adjust things in their everyday life that was once easier to attain.

Rewards and gratification exist for providing care for special needs individuals although stress may seem overbearing for some and outweighs the rewards. However, despite the challenges and difficulties that exist in caring for others who are disabled, it can be fulfilling task because caregivers may use this as a coping mechanism rather than looking at it as a burden which fulfills one's life internally. Hastings, Allen, McDermott, and Still (2002) point out that positive perception may function as a coping mechanism for stress and strains. However, the authors say that not very much research on rewards and gratification has been done therefore; it is an area that lacks information and needs to be studied more thoroughly.

Research Focus, Statement, or Question

This research will focus on stress among caregivers of individuals with special needs. Stress is a psychological condition that causes emotional and physical harm. Environmental negative factors such as personal relationships

(Lazarus & Folkman, 1987) job loss, death of a loved one or caring for a disabled individual all lead to emotional distresses. Individuals experience stress at some point in their lives, however, chronic stress can lead to prolonged depression and anxiety if left untreated. Therefore, identifying normal stress to chronic stress is vital for emotional and physical stability.

Caregivers are those who care for an individual that requires time, attention, energy, and assistance with activities of daily living. Activities of daily living include providing personal care such as bathing, feeding, toileting, giving medications, providing transportation services, and meal preparation (Davidhizar, 1994). For example, caregivers may be a son or daughter caring for a mother or father who has had a major life impact that requires constant monitoring. On the other hand, it may be a parent caring for a disabled child or young adult that needs around the clock care.

Individual needs refer to the personal needs of each disabled individual. For example, accommodating a home for wheelchair access or renovating a shower to provide bathing needs and easy accessibility are all part of a person's individual needs. In the United States, the American with Disabilities Act is a law that prohibits discrimination among the disabled and provides public accommodations (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004).

Stress is a real problem that affects caregiver's emotional and physical well-being, therefore being both emotionally and physically fit will help caregivers cope with stress effectively. Untreated stress can lead to psychological,

behavioral, and physiological effects that are associated with compromised immune systems and heart disease (Bevans & Sternberg, 2012). Therefore, caregivers should seek help, be emotionally, and physically well to avoid burnout, which may be defined as the mental or physical breakdown that is caused by being overly stressed, in the future.

Paradigm and Rationale for Chosen Paradigm

The perspective that the researcher is using is the post- positivist paradigm and a qualitative approach will be used to gather data. The study will focus on caregivers who care for a special needs individual and the stress it sometimes causes due to the pressures of other life factors. According to Morris (2013), the post positivism researcher

...takes the positivist paradigm as its starting point and, on the whole, accepts that worldview. It concurs that, indeed, an objective reality exists but suggests that the “immutable laws and mechanisms” driving that reality can never be fully comprehended. Post positivism’s associated epistemology suggests that one can never step completely outside human experience to study it (p.41).

Literature Review

The literature review focuses on the following areas: stress, burnout that is caused by caring for an individual with special needs, what parents do to

alleviate stress, the reward it is to care for a child with special needs, the therapeutic techniques clinicians use to help their clients cope with stress, and the outcomes clients have after receiving therapy.

Stress

Stress is a condition in which causes emotional and physical impairment that leaves a person feeling drained. Stress can be caused by any life impacting changes including caring for an individual with special needs. According to Spratt, Saylor, and Macias (2007) extensive research has been done that families of children with special needs are more susceptible to high levels of stress. While special needs is often associated with children, this can be caring for an adult children with special needs as well as caring for an elderly parent that has been impacted by an illness which requires complete care. Hoffmann and Mitchell (1998) say that conflicts between recipients and caregivers carrying daily activity routines was high and that social isolation, a decrease in health status for the caregiver as well as resentment and anger were present toward the parent.

Impact of Burnout on Caregivers

Burnout can occur at any given time if a caregiver does not take the right steps to care for themselves. Brodaty and Donkin (2009) say that caregivers are vulnerable to adverse effects that exacerbate burden and drain. For some individuals, stress causes extreme psychological and emotional harm that affect their self-esteem and autonomy. In addition, burnout can lead caregivers to

experience feelings of anxiety, depression, and fear about the future. Therefore, it is important for the caregiver to seek help when appropriate and develop self-care behaviors that will greatly reduce psychological conditions.

Respite care is a form of care that relieves stress and fatigue among caregivers caring for a dependent that has a disability (Doig, McClenna, & Urichuk, 2009). Caregivers need time to regroup and do other things other than staying at home all day caring for their loved ones. Respite care allows a “time out” for caregivers to take care of their personal and social needs. Hirsch, Davies, Boatwright and Ochango (1993) say that research on respite care is one of the most important unmet needs.

In order to normalize and prevent institutionalization of individuals with special needs, respite care must meet the needs of families of children with severe disabilities (Blacher & Meyers, 1983). Therefore, respite care is a great alternative to preventing stress from building up and getting out of control.

Parents caring for a child with special need benefit from respite care because it gives them a chance to do things that they are unable to do when caring for their child. Chan and Sigafoos (2001) found that parents enjoy a higher quality of life and are less likely to seek alternative placement for their child if they do not have respite care. Parents who sought respite care felt happier and spent their time having increased leisure activities and social interactions.

Therapeutic Techniques Used for Coping and Managing Stress

Clinicians such as licensed clinical social workers, licensed marriage and family therapists, psychologists, and psychiatrists often see clients due to stress. Whether it is work-related stress or stress caused by life in general, stress is the cause of emotional and physical impairments. In the end, it can be detrimental to one's health. Cognitive therapy is used to reduce anxiety and manage stress levels and has proven to be a safe and effective treatment for post-traumatic stress disorder (Harvey, Bryant, & Tarrier, 2003). Cognitive behavior is not the only method in treating stress disorders. Individuals need to recognize stressors and find therapeutic techniques to manage it before it manages them.

Another form of therapy that may be beneficial is massage therapy. Massage therapy is the oldest form of treatment in the world that originated from China, India, and Egypt (Field, 1998). Massage therapy works by manipulating tense muscles and relaxes the body relieving stress. There are particular areas where muscles tense up and that is the head, shoulder, and back area. Field found that massage therapy decreases cortisol that enhances the immune system and because most diseases are exacerbated by stress it might be an alternative method to reduce stress-related diseases.

Meditation is yet another method of coping with stress. Meditation is a practice that has been around for several thousand years in Eastern religions like Buddhism. It is used nurture the inner equilibrium of mind and spiritual growth (Miller, Fletcher, & Kabat-Zinn, 1995). Yoga guided practices, and tai chi are

only a few forms of meditation. They can be very useful at reducing stress. Other therapeutic methods social workers and other related disciplines use is “mindfulness-based stress reduction” (MBSR). MBSR is a “non-elaborative, present centered awareness in which each thought, feeling, and/or sensation that arises in the attentional field is acknowledged and accepted as it is” (Minor, Carlson, Mackenzie, Zernicke & Jones, 2006, p.94).

There were only four therapeutic techniques mentioned, however, there are much more techniques that clinicians use to help their clients alleviate stress that would require extensive research. Sometimes these therapeutic techniques mentioned above are not enough to alleviate stress and medication is required to by a licensed physician to enhance the individual’s well-being. Other factors that may cause high stress and anxiety levels are low serotonin levels that cause an imbalance in the brain chemistry in which medication along with other forms of therapy would benefit individuals. If left untreated, stress can cause immune deficiencies, digestive problems, and cardiovascular diseases (Imbalance, 2009). Their physician should evaluate individuals experiencing chronic stress before it becomes a major problem in their life.

Success of the Methods

Therapy success depends how well individuals respond to therapy and it also has to do with how well they will cooperate with clinicians to achieve goals that will help them cope with stress effectively. Successful therapy outcome also depends on the client/clinician relationship. Each clinician has their therapeutic

style and technique, therefore clients have to assess their individual needs and see if they are compatible with clinicians in order to have successful outcomes. Therapists that show credibility, empathy, and affirming clients as well as engaging with the patient's problems were highly related to successful treatment (Lambert & Barley, 2001). In addition, when a client associates therapists with authority figures in the past life that were supporting and loving, they develop a bond and attachment that helps complete therapy effectively (Horvath, 2000).

This literature review provided information on stress among caregivers of individuals with special needs, stress related to caring for a disabled person and rewards for caring for an individual with special needs. In addition, it discussed the therapeutic techniques used by clinicians for helping their clients cope with stress and if therapy is successful. The study focuses on exploring the different therapeutic approaches to avoid burnout and stress among those caring for individuals with special needs. Each individual is unique and is aware of what therapeutic approach works best.

Theoretical Orientation

Since the study relates to stress among caregivers caring for an individual with special needs, a theoretical approach on social support and coping would best fit into this study. Thoits (1986) defines social support as a function performed for distressed individuals such as family members, coworkers, friends, or neighbors. "Coping is viewed as an ongoing dynamic process that changes in

response to the changing demands of a stressful encounter or event” (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001, p. 275). Individuals experience stress in all aspects of life. Stress happens unexpectedly or may be on going depending on the circumstances one is facing at the time. Since most caregivers spend the majority of their time caring for a disabled person, stress is often imminent.

Social support and coping helps individuals feel autonomy and self-determination therefore; clinicians should help individuals cope with the stress that entails caring for a disabled individual including referrals to social support groups for their clients to help build self-esteem in order to cope with stress. With proper group therapy treatment, particularly one related to caring for disabled individuals, they could relate to others who care for individuals with special needs and can share ideas and take advice from others in the group to enhance their well-being that will greatly improve their overall health.

Contribution to Social Work Practice

This study contributes to both micro and macro social work practice. At a micro level, clinicians will better understand clients going through stress related to caregiving burnout. Clinicians working with stressed individuals will help their clients learn how to cope with stress effectively. It will also boost the client's confidence to deal with burnout by working together with the clinician to develop self-care coping techniques. At the macro level, communities can come together

by conducting stress coping workshops specifically for caregivers of individuals with special needs to enhance their well-being and at the same time relieve stress among others who are going through similar situations.

Summary

Chapter one focuses on the assessment phase in the post-positivist study in this research project. Chapter one provided information on the post-positivist paradigm and the awareness of stress related to caring for an individual with special needs. The literature review provided an overview on stress caused by caring for an individual with special needs and those who deal with it daily and what approaches clinicians take to help their clients deal with its effects. Finally, the first chapter explains the future contributions to the field of social work.

CHAPTER TWO

ENGAGEMENT

Introduction

This chapter discusses the engagement process between the researcher and the key players and it describes the researcher's engagement with the study site and the gatekeepers. This chapter also discusses the steps the researcher will take in order to collect data. Diversity, ethical, and political issues will be discussed as well as how technology plays a role in the engagement process.

Study Site

The research site for this project is at an agency that provides services for disabled adults and children in the Riverside County region. The clients of the agency are those who care or have cared for individuals with special needs on a day-to-day basis. Groups A, B, and C are organizations serving individuals with mild to severe disabilities ranging from 0-99 years of age. Group A is a for profit agency that accepts a variety of medical insurances, whereas, Group B and Group C are non-profit agencies serving children and adults with disabilities. Group B provides day programs, supported employment, and sports and recreation to help their clients develop some form of independence, while Group C is an organization who serves individuals with special needs particularly those with cerebral palsy. They strive to advance the independence and productivity.

Engagement Strategies for Gatekeepers at Research

Telephone and email was used in order to contact gatekeepers that work in an agency that work at the study site. The researcher went over the research project and gave the gatekeeper an overview of the study then set up a meeting in person to discuss the study being conducted. The researcher met with the director of the study site and provided detailed information and purpose for the study. The researcher briefed the gatekeeper on the focus of the study, the time it took to complete the interview and the impact and benefit to the site. Handouts of the study were provided to all participants with a short summary of the study being conducted.

This researcher cares for a child with special needs and can contact local agencies visited by the researcher to present the study and placed flyers to see who is interested in participating in the study. The flyer consisted of the institution, the type of participants needed, the time needed to conduct the interview, the reward, and the researchers phone number and email information. The researcher also knows parents who care for individuals with special needs and can develop a snowball effect to gather participants.

Self- Preparation

I interviewed caregivers who care for an individual with severe disabilities. I prepared for the interview and had a written layout as a guide to follow. I introduced myself to the participants; engage in a casual conversation before

starting the interview process, and began the debriefing and informed consent phase and finally ask a series of questions. I am looking to gain knowledge about people who have high levels of stress because of caring for individuals with special needs and what techniques caregivers use to help cope with stress. I had some knowledge on how stress affects individuals who care for a disabled child or adult and can engage with them by relating to their personal struggles and challenges.

Specific issues that were addressed are making sure that I asked questions that are not too sensitive and would not upset the participants. Another issue is that the interview must be with the caregiver alone and not the individual with special needs present because if they are disabled, but cognitively intact, they may feel offended by the answers provided to the researcher and may cause emotional distress. All measures were considered as to avoid any emotional or psychological harm to protect all human subjects. I have personal experience with caring for an individual with special needs and may affect the research process by bringing up empathetic feelings that may cause me to become emotional. I set aside personal feelings and focuses on the participants responses attentively. My professor helped to design questions that were free from bias.

Diversity Issues

Diversity issues are important in conducting a research project. The researcher is the caregiver of a child with special needs can relate to individuals who are going through the same situation. Some of the diversity issues related to this study are the how each group copes with stress differently. Since the majority of people in Riverside county are of Hispanic and of Latino cultures, it may be that there may not be a diverse group of individuals and the focus may only be on a specific group of individuals.

I sought to gather a diverse group of people in the study so that the research can be diverse. I sought agencies that assist individual with special needs in the Eastern part of the county where there is the majority part of Hispanics as well as the Western part where there are white and African-American, and those of the LGBT community. I was unable to interview African-Americans or of LGBT communities. I treated participants in a respectful matter by not being bias or passing judgement based on the answers of the participants and based on my view of each ethnicity and community.

Ethical Issues

I completed a human subjects review to prevent any ethical issues. I had the participants sign an informed consent and informed participants that all information is confidential. The data gathered remained in a lockbox that I purchased and only I had access to the information. I also had participants sign a

consent giving me permission to record the conversations for the purpose of data collection. The participants were also notified of why the study is conducted and their role in the study. I protected the confidentiality of individuals by not providing any names of the participants or specific information related to the study. Private information, such as the diagnosis of the person with special needs, is shared only with permission of the participants. Again, all information remained in a secure and safe place.

Political Issues

Political issues may arise during the course of this study. Groups A, B, and C may want to find out the responses from some of the participants. The agencies may become cautious toward me because of a potential negative impact toward the site. The research site may look at me differently after my relative is a client of one of the agencies. After the findings of the study, they may want to have minimal interaction with me and may react negatively toward the client and me. I respected the agency and the clients it serves by protecting and keeping all information confidential.

The Role of Technology in Engagement

The use of technology was applied in this study. I used phone and email to contact gatekeepers. I established rapport with the participants to conduct

face-to-face interviews. The audio recording also took place while interviewing the participants with their permission.

Summary

The engagement chapter includes the location sites and the participants used in the study. I also discusses the steps taken to make contact with the gatekeepers. I briefed the gatekeepers of the study. Possible diversity, political, and ethical issues are identified. The use of technology in this study is laid out.

CHAPTER THREE

METHODS

Introduction

This chapter describes the implementation of this study. The study will include the descriptions of the research site as well as the study participants, data gathering, and phases of data collection and data recording. Furthermore, a follow up interview with caregivers used in the study would allow me to see if the stress decreased once they received therapy and if they are better able to deal with stress. Termination and follow up will be discussed in this chapter.

Study Participants

In the Southern California region, particularly in the desert area, there is a high population of elderly individuals. The majority of this population lives in senior communities and private country clubs and is of high economic status. The baby boomers that live in this area are of middle/upper class who work in the medical field such as physicians, nurses, physical and occupational therapist. The lower class is individuals who work as farm laborers and migrate to the Northern regions to follow the fruit and vegetable harvest. The client group that I gathered data from is a variety of individuals from different ethnic and economic backgrounds.

The study participants chosen are those of agencies of caregivers who care for disabled individuals. The participants came from different family backgrounds, socio-economic status, and various education levels. I gathered a number of participants of a diverse group so that the study will not only focus on one specific group of individuals. One of the agency sites provided statistics of the type of clients they serve. The income level categories ranges from extremely low, very low, low, moderate and high. The extremely low income percentage is approximately 27% with a median income of \$16,100 per year, very low is 21% with an income of \$26,800, low is at 17% with a median income of \$42,900, moderate income is at 12% with an income of \$62,400 and last is a high income level of 23% of over \$62,400 (personal communication, July 10, 2018). These percentages are based on an average of two individuals per household.

In the category of gender, the agency serves approximately 62% of males and 38% of females. The ethnicity group is of Anglo/white at 72%, Hispanic at 19%, Black/African American at 6%, American Indian/Alaskan Native at 0%, and last Asian/Pacific Islands at 3%. Finally, the age range is as follows: under 35 years of age 2%, 35-34 years of age 19%, 55-74 years of age 46% and 75 and older 33% (personal communication July 10, 2017). Caregivers of either adults or children were eligible to participate in the study as long as there is a special need that significantly affects the caregiver's life by caring for a disabled individual.

The number of participants and the age range were 18 years to 70 years of age or older. Each participant was of diverse backgrounds that have been

caring for a disabled individual for longer than one year. The interviews came from families of agencies that serve children and adults with severe disabilities. Caregivers who care for a disabled individual for more than 40 hours a week were considered for this study. The services that the caregiver provides included bathing, feeding, cooking, cleaning, and providing transportation to and from doctor's appointments.

Caregivers often experience financially, emotionally, physically burnout and interviewing caregivers helped me to understand how they deal with the stress of this demanding task and clinicians can have a better understanding of helping caregivers cope with stress before it gets out of control. For example, the stress that often caregivers face is fatigue, insomnia, stomach complaints, back problems due to lifting, and depression.

Additionally, I can gain a better understanding on the effects of stress one has when caring for an individual with special needs and I gained knowledge in the process to help future clients cope with these life stressors. Caregivers who were willing to participate completed an interview. The interview consisted of answering a few questions on their own experience on stress related to caring for a disabled person.

Selection of Participants

I selected the participants from various agencies that serve disabled individuals the desert area. I selected participants in both the Eastern and Western part of the desert area in order to have a diverse group of individuals as

participants. The participants were male and female caregivers who care for an individual more than 40 hours per week. There was a \$5 Starbucks gift card for participating in the study.

The purposive sample that was used in this study is the maximum variation sampling for this study. The reason that I used this sampling is to “identify the diversity of experiences with a social phenomenon and gives in depth descriptions of unique cases as well as any important shared patterns that are common to diverse cases (Morris, 2013, p. 124). The intent is to gather experiences that are unique to each caregiver and learn their different coping mechanisms. I selected participants of a diversity background such as education, social economic status, religious affiliation, marital status, and employment status.

After the Human Subjects Committee approved this study, the gatekeepers placed a flyer at their agency informing potential participants of the study being conducted. The flyer had a brief explanation on what the study is about, how long the interview will take as well as the incentive being provided and the contact information of the researcher so participants can contact the researcher at their own will. The gatekeepers also had a general idea of what the research study is about and they also contacted the researcher to meet with potential participants who are interested in participating in this study. This researcher created a word document of the overall review of the study and handed it out to the agencies gatekeepers so if the potential participants have

questions before contacting the researcher, the gatekeeper can provide them with this information to see if they are still interested before taking the next step in contacting the researcher.

Data Gathering

The data gathered in this study was qualitative data through face-to-face interviews with caregivers who care for a disabled individual. The interviews with caregivers were conducted at the study site or a place where they feel comfortable such as a coffee shop. The interview consisted of approximately ten questions.

The interviews conducted in this research were recorded by a tape recorder and this researcher closely analyzed the answers given. The caregivers were asked questions on how their life had been impacted by caring for a disabled individual and if they experience high levels of stress, if they have sought help and what they can do to better cope with stress. The study answered the following questions such as the severity of the condition of the person they care for, if they have sought outside help to relieve them from their duties, and if their stress levels have affected their life to seek professional help.

The questions on the interview conducted to caregivers are on Appendix A of this project. These questions helped the researcher gather information on the experiences the caregiver has caring for a disabled individual. Throw away and probing questions were used initially so the participants may feel comfortable

with the researcher. Then the participants were ready to answer the questions that were used to collect data, which gave the researcher the information needed for this study.

Phases of Data Collection

This researcher used the post-positivist approach and the data collection is qualitative. The first phase consisted of contacting gatekeepers of various agencies to see who was willing to participate in the study. The researcher emailed the agencies gatekeepers and emailed the flyers that they posted in order to gather participants. This researcher visited the agency site and introduced herself to the gatekeepers to build rapport. Eventually face-to-face interviews were scheduled. The first part of the data collection consisted of collecting demographic information and the second part consisted of gathering information regarding caregiving experiences.

During the second phase of the researcher study, which took six months, this researcher gathered data from interviews by face-to-face interviews. All questions were conducted in English and Spanish. This researcher is fluent in Spanish and was able to translate all material. This researcher took notes taken from audio recordings as well as written notes from those participants who did not wish to be recorded. All material collected were shredded and the audio recording were erased in order to protect any identifiable information.

Data Recording

This researcher provided a list of questions to the participants the face-to-face interviews and conducted an interview for caregivers caring for a disabled individual. This researcher used an audio recording device after obtaining consent from the participant. If the participant did not wish to be audio recorded, the researcher wrote down the answers on a journal with dates and times that the researcher interviewed each participant.

Data Analysis

This study used a post positivist approach using qualitative analyses data. The approach used was the bottom up analysis to give context to the data findings and to build from the data, noting what is taking place within the research. The bottom up analysis has four different stages: open coding, axial coding, selective coding, and conditional matrix.

Open Coding

According to Morris (2013, p.257), “open coding is an inclusive process of gathering data from several key players.” In this section of this study, the researcher needs to read the data several times and then start to create tentative labels or chunks of information that the researcher sees happening. The following are examples of opening coding are: services caregivers provide, challenges faced, seeking help, self-care.

Axial Coding

In this section of the research study, the researcher needed to make sure to write down word for word the answers given by the participants and compare them with other answers to see if they are similar to other responses. If the responses are similar then there is no need for repetition of all similar answers on my study, but sum up everything in a sentence or two and move on to the next phase of the research. Examples of axial coding in the data gathering can be broken up into the following: caregiving stressors, what coping techniques are used if any, willingness to take time to do something they like, willingness to seek help when experiencing high levels of stress. This information helped the researcher form a connection with the different responses given by the participants.

Selective Coding

In this section of the research, is where the core theme is identified. The stage in this process is to identify the patterns the caregivers are making. Identifying their feelings and statements from the beginning will help to analyze data.

Conditional Matrix

The final stage in this post positivist study is conditional matrix. This is where the researcher indicates how the study is used in a micro and macro social work practice. Caregivers in this study deal with individuals who are disabled on a daily basis. This matrix links the findings of this study to human

experiences. This study will help future clinicians to identify stress among caregivers and will to help them with coping techniques that will be beneficial to their overall health.

Termination and Follow Up

After interviewing each participant, the termination process included answering any questions the participant may have and reiterated that all information discussed between the researcher and the participant is confidential. This researcher thanked the participants for participating in the research study. This researcher provided the participants with feedback and provided the results of the study once they become available.

Communication of Findings and Dissemination Plan

The participants were able to call the researcher for the results of the study. Once the study is finalized and upon request, the participants were provided with a website link of the full study for them to view at their own time. This research study was published and archived in the California State University San Bernardino Scholarworks website.

Summary

Chapter three discusses the implementation stage of the study and identifies the sites used, participants, data collection and data analyses methods

of this study. The interviews were conducted face-to-face. An incentive was offered for participating in this study. The data collected was recorded with the permission of the participants and documented written notes were kept in a journal. Finally, the participants were thanked for their participation in this study and were terminated. This researcher provided her personal phone number to the participants in case they have any questions.

CHAPTER FOUR

RESULTS

Introduction

This chapter provides the results of the study regarding caregiver's psychological health and their coping mechanism for caring for an individual with special needs. The results were gathered by providing demographic questionnaires to participants in order to find out their age range, race and ethnicity, gender, economic background, employment and marital status, and education level. Caregiver's emotional responses and coping skills were acquired through qualitative interviews. Specific themes were gathered from the interviews such as service utilization, social support systems, mental and physical health, self-care. The researcher uses participant quotes to highlight the themes listed above. The participant's quotes provide a better understanding on each caregiver's experience on emotional well-being, and how they cope with the stresses associated with caring for a person with special needs.

Demographics

The participants gathered in this study are caregivers of parents or children with special needs. Each participant was assigned a number from one to eight in order to identify them. In this study, there are eight participants. One participant was male and the remaining seven were female. All participants were

either caregivers of parents or parents of children with special needs and described themselves as the primary caregiver. Four participants identified themselves as Hispanic in ethnicity and four identified themselves as Caucasian in ethnicity. The participant's current age range was from 25 to 65 years of age or older. The participant's average age is 42, the median age is 42 and the range in age is 39.

Concerning education levels, three of them had "less than high school" education, three had "bachelor's degree" and two had "master's degree." In regards to the participant's yearly household income, four participants made less than \$25,000 per year, one participant's income range is \$35,000-\$49,000, two participant's yearly income is \$75,000-\$99,999 and one participants household income ranges from \$100,000-\$149,000. The primary language for 75% of the participants is English, while 25% primary language is Spanish. Finally, in regards to employment status, two participants identified as "currently not employed", two participants identified as working "35 hours a week or more" and four participants identified as working "less than 35 hours a week."

The participants identified as primary caregivers for individuals with special needs. Two participants cared for a parent with Alzheimer's, one participant cared for a parent who had a stroke, and five participants cared for a child with developmental and physical disabilities. For the participants caring for children, two of the children were diagnosed with autism, one had an unbalanced translocation, monosomy 6 and trisomy 16, one identified her child

having a chromosomal disorder, and finally one identified as her child having polymicrodysplasia.

Qualitative Interview Data

Once the participants had completed the demographic questions, participants were interviewed using eleven open-ended questions. The interviews ranged from 9 minutes to 24 minutes with an average of 20 minutes. The participants were asked to share their caregiving experiences and their overall emotional, physical, and mental well-being. They were asked about the challenges they faced and what they did to care for their own personal needs. The following categories were used to explore in depth how it had an impact on caregivers: service utilization, social support systems, mental and physical health, and self-care.

Service Utilization

All participants were asked if they had used respite services like private or state funded services so they may be able to work or do other out of home activities. Six of the eight participants had received respite care services. One of the participants was in the process of receiving services when this interview was conducted and one participant did not have any services. For example, Participant 2 said:

It was really difficult to receive services in the beginning to tell you the truth but thank God, I actually have one of my in-laws that she went to

school to care for patients with special needs. It takes a long time to be able to trust somebody into your home, into your daughters care because you are basically putting her whole care in somebody else's hand per se so it's difficult to trust somebody within a day to the next. I mean it takes months I think to develop that trust. In my case, I was able to get someone I know to care for my daughter.

Participant 3 found that adult day care for her mother with Alzheimer's was a benefit for her to be able to work outside the home. Participant 3 stated:

I was able to take my mother to adult daycare. So I would just have to wake her up at 5:30 am and get her cleaned up and dressed and feed her breakfast and then drive her to the daycare. Then I would go to work. Then she would be at the daycare all day and then I would pick her up before 5:00 pm and take her home.

Since not all individuals qualify for state assistance such as In Home Supportive Services (IHSS), those who do have respite services through this agency provides some relief for individuals caring for a loved one. Participant 1 said the following:

I have assistance to care for my mother. I have someone who is hired by the county who comes to help me out while I am at work, however, after I get off work; I am the one who has to attend to her needs. If I did not have this service; I would not be able to work outside the home. At least while I

am work, I think of other things other than the responsibility of coming home and caring for my mother.

Participant 5 who has respite services for her daughter while she was attending school stated the following:

So I am the provider and I do have help. She has a nurse. Her nurse was with her a few days after getting out of the hospital. It was very anxiety-provoking having a stranger coming into my home. However, I was blessed enough that we had a really amazing nurse.

Social Support Systems

Of the eight participants, four said they had a good social support system to assist in caring for their loved ones with special needs. The other four stated that they did not have much support. Those who did have that extra help from family members or friends expressed their gratitude in having the help and felt less stressful. For example, Participant 4 said the following:

Family wise, I was really close to my family at that time. My mom and stepdad were very supportive. My aunt was really involved in our lives. She visited my daughter in the NICU every day, and then she helped me out a lot at home after she was released from the hospital. Once a week, she would come to my home and help me fold laundry. My mom also helped me at home.

Similarly, Participant 6 stated that multiple people assisted her in caring for her son. She stated the following:

Multiple people assist me in caring for my son. My mother-in-law, my husband and a nanny. That is a huge weight off my shoulders because it is hard to care for a child who is disabled. Not a lot of people are willing to help, but I have been blessed with people who are willing to do that.

On the other hand, there were participants who did not have any support and had to care for their loved ones on their own. For example, Participant 7 says,

I am the only one that cares for my father. I am his IHSS provider and I am pretty much with him 24 hours a day 7 days a week. It is hard for me to do what I want because I just do not have that support. If I go somewhere, I have to take him with me because I cannot leave him alone. It is not an easy task being a caregiver all the time.

Participant 3 says,

I had a sister that did help for a little while until my mother, her Alzheimer's got bad, and then my sister could not bear anything that had to do with cleaning up stool, and that was the end of that. She could not do anything anymore. So it has pretty much just been me caring for her.

Mental and Physical Health

Of the eight participants, seven said they experienced some form of mental or physical decline in their health. Some participants stated that they had to make some kind of life adjustments to cope with the stresses of caring for their

loved ones. A few stated that they had to seek professional help such as therapy or pharmacotherapy or both. Participant 6 said:

Yes. It is in general, I have gone through many things. I dealt with postpartum depression after my daughter was born, but in general, yes, I suffer from depression. It was never debilitating because I had to get up and move, but definitely to the point where I thought about taking my own life.

Participant 7 stated:

...well yes, yes it has affected me much emotionally in caring for my dad because I cannot do many things because I have to be with him and sometimes I do not travel because of this. I cannot go out with my children because I do not have anyone to care for him.

Participant 8 said:

I have had some difficulties at times. I am currently on an antidepressant which helps because I found that my stress was causing me—the way my husband described it is I was yelling all the time. So I've been on the antidepressant and it's been very helpful, it's been several years. I have had to go on a medical leave in the past because of mental stress issues, yes.

Similarly, participant 3 said:

I don't know that I would call it either one of those things [referring to depression or anxiety]. I just remember that I go to the point where I

walked up into the office one day and said, “Put me on part-time or I’m quitting today.” Because I knew, I was at the limit. But I wasn’t depressed. I knew that I was physically, emotionally exhausted. And I got part-time. So that helped.

Participant 1 said that he had been exhausted because after work he had to come home and attend to his mother’s needs. He said:

I feel tired. I need time to relax so I can renew myself physically and mentally. It is exhausting, tiresome, and frustrating and one has to be careful not to let their emotions get out of control because it affects everyone. I have felt minor depression, but I try to control it and not let it interfere with my life. Mentally it is draining to care for my mother, but I cannot just stop doing it; I have to continue caring for her.

Self-Care

Of the eight participants, only three practiced self-care to help them cope with the stressors of caring for an individual with special needs. Participants reported self-care by getting a pedicure, having alone time to read, or going on a vacation. For example, Participant 5 stated:

Once in a while, I do go out. But I have to really plan it in advance. It has to be carefully planned. So sometimes I don’t get invited because I always say no. So that has changed a lot. And then, even me and her dad, a date for us it’s rare. And when we have it we just kind of get excited. For my own needs, for me, I like to do things for myself like go get a massage, get

my nails, my pedicure, go out shopping. I love that; retail therapy. I don't have much financial resources for that but I do like to do that for myself. Go have a drink, go with my friends. And for a while with school, that was therapeutic because I was just thinking about my assignments and what I have to get done, talking to my colleagues.

Participant 3 said:

Well, a couple times a year I would have one of my sisters come and stay at the house and myself and my daughter and her husband and grandkids would go on nice vacations. We went to very nice places. And then sometimes if I had something to do in the night, my brother who lives locally would come and stay.

Participant 8 added:

Our social life has been greatly impacted because not everybody understands. People are afraid of different and my daughter's behaviors were pretty extreme at times and I find out that others are not receptive even when you explain they're afraid. So I find that it's really myself, my family and those folks who really, really care about me is my social life. I love to read, I like quiet time. My escape is just I love to read. I'll take myself out for a Starbucks or something. I do appreciate my alone time.

Conclusion

Chapter four presented the results of this study regarding caregiving experiences and their overall emotional, physical, and mental well-being as well as their social support systems and what they did for self-care. The results of this study were gathered from a sample size of eight participants who identified as caregivers of individuals with special needs. Demographic information was presented along with their open-ended responses. Four classifications were drawn out of the transcribed information. The themes were service utilization, social support systems, mental and physical health, and self-care. The results will be discussed in detail in Chapter five.

CHAPTER FIVE

DISCUSSION

Introduction

The final chapter will provide a general insight of the main themes found in this research and the impact it has on how it relates to caregivers caring for individual with special needs. This chapter examines how caregivers cope with the stress that entails in caring for an individual with special needs and what caregivers due to care for the psychological and emotional health. Limitations of this study are discussed in this final chapter as well as recommendations for social workers working with this population.

Service Utilization

In looking at service utilization such as respite services provided by either private or state funded, this study found that six of the eight participants had such services in order for them to work outside the home. The support came from agency nurses, agency workers, and adult day care centers that were able to provide the care needed for these special needs individuals to be able to work while their loved ones were safely cared for. The participants in this study were able to have the respite care needed to do other things needed to care for themselves and avoid burnout. Cowen and Reed (2002) found that increased stress levels and depression correlate with excessive caregiving demands for parents caring for a child with developmental disabilities. Cowen and Reed

(2002) further reported that this might lead to child maltreatment and placing the child in foster care homes that will meet the needs and demands of the disabled child.

Burdz, Eaton, and Bond (1988) found that caregivers who use respite care services reported better improvement in their physical and mental health and experienced increased confidence in their ability to continuing taking care of their loved one. Furthermore Mason et al., (2007) stated that caregivers were satisfied with respite services; however, for those who do not receive government assistance, this may be quite costly. For caregivers who do not qualify for paid government assistance programs it may be difficult to pay for out of pocket services leaving the caregiver to consider other alternatives.

Social Support Systems

In regards to social support systems, four of the eight participants stated they had good support from friends and family members. Having a good support system enhances the overall well-being on caregivers because they know they can count on others to step in and assist when needed. Those who have this type of support experience less stress and mental challenges.

Grant, Elliott, Newman-Giger, and Bartolucci (2001) found that inadequate social support is associated with caregiver distress. Further, caregivers who have good social support were more likely to have life satisfaction than those who did not have any support at all. By using problem-solving interventions within their social support group network, they are able to cope with caregiving stressors.

Mental and Physical Health

In regards to mental and physical health, seven of the eight participants stated that they had some form of mental and physical health problem. It is common for caregivers to experience some form of mental or physical health problem such as stress, depression, anxiety, or physical health problems such as back pain if the individuals they care for are not mobile. Another form of mental problem that caregivers face is caregiver burden or burnout. This in turn could lead to neglect and possible emotional, verbal, or in extreme cases physical abuse.

Caring for an individual with special needs have both mental and physical consequences. Physical health is poorer than non-caregivers and they have higher rates of psychological distress such as depression (Goode, Haley, Roth, & Ford, 1998). Furthermore, the authors point out that another source of stress to the caregiver is patient behavioral problems and memory impairments making it harder to handle if they are out in public.

Self-Care

Concerning self-care, only three of the eight participants practiced it. Self-care is important when caring for individuals with special needs. Whether it is going out with friends or finding the time for one-self to read a book, self-care is essential to avoid caregiver burden or burnout. Research has found that family taking care of loved ones with special needs takes a toll on physical, emotional, and psychological health (Acton & Wright, 2000). Acton (2002) defines health

promoting self-care as “those actions persons take to improve their health, maintain optimal functioning and increase general well-being (pp. 73)”. The importance of self-care is evidence-based and something that should not be taken lightly.

Limitations

This research project had a few limitations. One limitation was the study's sample size, which consisted of only eight participants. Another limitation that is noted is that the study had only Hispanic and Anglo Americans. This provided little insight on the perspective of other ethnicities and their perspective of caring for individuals with special needs. A final limitation is the perspective of men's point of view when caring for their loved one. This study mainly focuses on women and the care they provide to their loved ones. However, only one male participated in this study. Perhaps by having more input on men's perspective, the study would have provided a better understanding on the hardships they face by providing care for their loved one and how they handle their emotional well-being.

Implications for Practice

Implications for this study on a macro level are that policies and procedures should be in place when working with individuals with special needs. Special needs individuals are a vulnerable population and perhaps more

literature on the subject could help social workers work with this population. On a micro level, social workers should study more on the subject on caregivers and the individuals they care for and the stress it causes on both the caregiver and the individuals they care for. Furthermore having policies that support caregivers getting respite is important. Practitioners should help caregivers find support network and other outlets that will help individuals cope better with stress. Future research in examining the relationship between social networks and caregivers who face stress should be considered.

Furthermore, licensed clinical social workers and other disciplines should have some knowledge on stress among caregivers caring for individuals with special needs. Social workers should be aware of coping strategies that individuals caring for special needs persons face on a day-to-day basis. Those coping strategies include service utilization, social support systems, mental and physical health, and self-care.

Recommendations

Recommendations for social workers are to become familiar with caregivers and the stressors they face daily. It is important for social workers to have an open communication when working with caregivers so caregivers can express their feeling more effectively without feeling judged. Furthermore, social workers should develop cues so they can better assist clients. Managing stress at an early stage can help avoid other mental health concerns in the future.

Conclusion

This final chapter reports the findings of this research project. The common themes reported in this chapter are from the participants in this study. The themes include service utilization, social support systems, mental and physical health, and self-care. Analysis of the data and limitations were addressed in this chapter. Finally, the need for social workers to understand stress among caregivers is also reported in this final chapter.

APPENDIX A
STUDY MATERIALS IN ENGLISH

INFORMED CONSENT

The study in which you were asked to participate is designed to examine stress among caregivers caring for an individual with special needs. The study is being conducted by Ida Benavides under the supervision of associate professor Carolyn McAllister, school of social work, California State University, San Bernardino. This study has been approved by the institutional review board social work sub-committee, California State University, San Bernardino.

PURPOSE: The purpose of the study is to examine stress among caregivers caring for individuals with special needs.

DESCRIPTION: Participants will be asked a few questions on the stress levels they experience while caring for an individual with special needs, how severe the individual's special needs are, if they sought professional help if their stress levels became to overbearing, if they have any outside help such as a friend, relative³, neighbor, etc., what they do for themselves to relieve stress, and some demographics.

PARTICIPATION: Your participation in this study is voluntary. You can refuse to participate in the study or discontinue your participation at any time without any consequences.

CONFIDENTIALITY OR ANONYMITY: Your responses will remain anonymous and data will be reported in group form only.

DURATION: It will take 30-45 minutes to complete the interview.

RISKS: There are no foreseeable risks to the participants.

BENEFITS: There will be a \$5 Starbucks gift card for participating in this study.

CONTACT: If you have any questions about this study, please feel free to contact Dr. Carolyn McAllister at 909-537-5559.

RESULTS: Please contact Dr. Carolyn McAllister (email: cmcallis@csusb.edu), or the Scholarworks database at the Pfau Library California State University San Bernardino for the results of the study after June 2019.

This is to certify that I read the above and I am 18 years or older.

| | |
|----------------------|-------|
| _____ | _____ |
| PLACE AN X MARK HERE | DATE |

I agree to be audio recorded _____YES _____NO

DEBRIEFING STATEMENT

The study you have just completed was designed to investigate stress among caregivers of individuals with special needs in the Riverside County area. We are interested in learning what type of stress levels caregivers face day to day challenges caring for a disabled loved one. We are also interested in what type of help they sought whether it is professional or personal to relieve some stress. This is to inform you that no deception is involved in this study.

Thank you for your participation. If you have any questions about the study, please feel free to contact Dr. Carolyn McAllister at 909-537-5559. If you would like to obtain a copy of the group results of this study, please go to the Scholarworks database at the Pfau Library California State University San Bernardino for the results after June 2019.

English Interview Questions

1. Whom do you provide caregiving services for? i.e., mother, father, daughter, son, brother, sister, etc.
2. How long have you been caring for this individual? Despite of the amount of time you have been caring for this individual (months or years), how has your life changed while caring for your loved one?
3. What type of services do you provide on a daily basis? Does taking care of this individual limit you from working outside of the home? What type of difficult situations have you dealt with while caring for this individual?
4. Are you the only provider or does someone else assist you? Have you ever considered respite services such as In Home Supportive Services? How do you feel having a total stranger come into your home to provide respite care from the daily activities you provide for this individual?
5. How has your life changed with this experience (emotionally, physically, and mentally)? Describe in what way your life has changed both positively and negatively. Do you feel that at times a lot of work? Do you feel overwhelmed?

6. What type of challenges have you faced in your social life caring for this individual? Do you have a break from caring for your loved one? If so, what do you do for yourself to care for your personal needs? How has caring for your loved one affected you financially?
7. Have you ever experienced mental health issues such as depression or anxiety because of this? If you have, how severe has your depression or anxiety been? Has it been so severe that you cannot function on a daily basis?
8. What do you do when you feel fatigued? Have you ever asked anyone for help such as relatives, neighbors, or a respite care agency? Do you turn down any help because you feel that no one else will be able to care for this individual as you do? Do you distrust others to care for your loved one?
9. Have you ever sought professional help that has experience with stress such as a psychologist, therapist, or any other professional? If you have not sought any professional help, have you considered going to support group or have you talked to a priest, rabbi, pastor, or any other religious leader?

10. Has caring for your loved one limited you from doing the things you like to do? If so, in what way have you been limited to do fun activities? What are those limitations?

11. If you had the opportunity, what things would you like to do? Go on a vacation, take a class at the local community college, or take up a hobby?

Developed by Ida Benavides

Demographic Questions

12. What is your age?

18 to 24 years

25 to 34 years

35 to 44 years

45 to 54 years

55 to 64 years

Age 65 or older

13. What is your race/ethnicity?

African American

Asian

Hispanic

Pacific Islander

White

14. Are you of Hispanic, Latino, or Spanish origin?

No

Yes

15. What is your gender?

Female

Male

16. What is your yearly income?

Less than \$25,000

\$25,000 to \$34,999

\$35,000 to \$49,999

\$50,000 to \$74,999

\$75,000 to \$99,999

\$100,000 to \$149,999

\$150,000 to \$199,999

\$200,000 or more

17. How many hours per week do you USUALLY work at your job?

35 hours a week or more

Less than 35 hours a week

I am not currently employed.

18. What is your marital status?

Single (never married)

Married

Separated

Widowed

Divorced

Living together

19. What is the highest degree or level of education you have completed?

Less than high school

High school graduate (includes equivalency)

Some college, no degree

Associate's degree

Bachelor's degree

Ph.D.

Graduate or professional degree

Developed by Ida Benavides

APPENDIX B

STUDY MATERIALS IN SPANISH

CONSENTIMIENTO DE INFORME

Este estudio en cual usted ha sido requerido para participar esta diseñado para examinar estrés sobre cuidador que cuida individuos de necesidades especiales. El estudio será conducido por Ida Benavides bajo la supervisión de la Asociada Profesora Carolyn McAllister, Escuela de Servicios Sociales, Universidad del Estado de California San Bernardino. El estudio ha sido aprobado por parte de la Junta de Revisión Institucional Sub-comité de trabajo social, Universidad del Estado de California, San Bernardino.

Propósito: El propósito de este estudio es para examinar el estrés sobre cuidador que cuida individuales de necesidades especiales.

DESCRIPCION: Los participantes contestaran varias preguntas sobre los niveles de estrés que sienten sobre el cuidado de individuos con necesidades especiales, que tan severo es la necesidad especial del individuo, si han requerido ayuda profesional por el estrés, si tienen ayuda como un amigo(a), pariente, vecino, etc., que hacen para sí mismo para el alivio de estrés, y algunos demografías del participante.

PARTICIPACION: Su participación en este estudio es totalmente voluntaria. Usted puede parar o discontinuar su participación a cualquier tiempo sin ninguna consecuencia.

CONFIDENTE O ANONIMATO: Sus respuestas serán anónimas y los datos serán reportados en forma de grupo nada más.

DURACION: Se tomara de 30-45 minutos para completar la entrevista.

RIESGOS: No habrá previsible de riesgos al participante.

BENEFICIOS: Se le dará una tarjeta de \$5 al Starbucks por su participación en este estudio.

CONTACTO: Si usted tiene alguna pregunta sobre este estudio, por favor siéntase con confianza de contactar a la Dra. Carolyn McAllister al 909-537-5559.

RESULTADOS: Por favor contacte Carolyn McAllister (email: cmcallis@csb.edu), o al Scholar works base de datos en la biblioteca Pfau, Universidad del Estado de California San Bernardino para los resultados de este estudio después de Junio del 2019.

Esto certifica que he leído el consentimiento de informe y so mayor de 18 años de edad.

Marque una X aqui

Fecha

Yo he consentido ser audio grabado (a) _____si _____no

Declaracion de Interrogatorio

Este estudio que usted ha completado fue diseñado para investigar sobre el estrés de cuidadores que cuidan a un individuo con necesidades especiales en el condado de Riverside. Estamos interesados en aprender cuál es su nivel de estrés como cuidador que usted enfrenta en su vida cotidiana y retos cuidando a su ser querido con discapacidades. También nos interesa saber si usted ha recibido ayuda profesional o personal para el alivio de estrés. Esto es un informe de que no hay ningún engaño en este estudio.

Gracias por su participación. Si usted tiene alguna pregunta sobre este estudio, siéntase con libertad de comunicarse con la Dra. Carolyn McAllister al 909-537-5559. Si desea obtener una copia de los resultados de este estudio, por favor vaya al Scholarworks Biblioteca Pfau en la Universidad del Estado de California San Bernardino después de Junio del 2018.

Spanish Interview Questions

1. A qué persona le provees servicios de cuidado? i.e., madre, padre, hermano (a), hijos
2. Cuanto tiempo tienes cuidando a esta persona? Sin importar el tiempo que has cuidado a este individuo, como ha afectado tu vida cuidando a tu ser querido?
3. Qué tipo de servicios provees a diario? El cuidado a diario te afecta para no poder trabajar fuera de casa? Qué tipo de situaciones difíciles as confrontado al cuidar este individuo?
4. Usted es el único proveedor o tiene asistencia? Alguna vez ha pensado en servicios de descansó como Servicio Sociales de Cuidado en Casa? Como se siente que un extraño venga a su casa para darle tiempo de descanso de sus actividades de a diario con su ser querido?
5. Como ha cambiado su vida con esta experiencia (emocional, físico, y mental)? Describe en qué manera ha cambiado su vida en forma negativa o positiva? Se encuentra que a veces es demasiado para usted y se sienta que es muy duro el trabajo? Se siente abrumado?

6. Qué tipo de retos en su vida social ha tomado por cuidar a ser querido. Tiene la oportunidad de tomar un receso en cualquier tiempo para cuidar sus necesidades individuales? Como le ha afectado económicamente el cuidado de su ser querido?
7. Alguna vez esta experiencia le ha causado alguna enfermedad mental como depresión o ansiedad? Si ha sido así que tan severo ha sido su enfermedad mental? Ha sido tan severo que no puede hacer sus funciones de a diario?
8. Que cosas hace cuando se siente fatigado (a)? Alguna vez le pide ayuda a sus familiares, vecinos, o alguna agencia de servicios de cuidado? Usted alguna vez rechaza la ayuda por temor que alguien no pueda proveer los mismos servicios que usted provee a su ser querido? Usted siente desconfianza de otros seres al cuidar de su ser querido?
9. Alguna vez ha buscado ayuda profesional con una persona que tiene experiencia sobre estrés como un psicólogo, trabajador social, o algún otro profesional? Si no ha buscado ayuda, alguna vez ha tratado de asistir a un grupo donde le ofrecen apoyo o a visitado a un sacerdote, pastor, rabino, u otro líder religioso para hablar?

10. El cuidado de ser querido le ha limitado de disfrutar de las cosas que le gusta hacer? De que manera? Que son esas limitaciones?

11. Si tuviera la oportunidad, que haría para sí mismo que le gusta hacer?
Que cosas haría si tuviera la oportunidad? i.e., tomar vacaciones,
tomar un curso en el colegio, o escoger un hobby.

Developed by Ida Benavides

Estadísticas Demográficas

1. Cuál es su rango de edad?

18 to 24

25 to 34

35 to 44

45 to 54

55 to 64

Edad 65 o mayor

2. Es de origen Hispano, Latino, o Español?

Si

No

3. Que es su estado marital

Soltero (a) (nunca casado (a))

Casado (a)

Separado (a)

Viudo (a)

Divorciado (a)

Juntado (a)

4. Cuál es su nivel más alto educativo?

Escuela de Secundaria

Preparatoria

Estudios universitarios, sin título

Bachillerato

Maestría

Doctorado

5. ¿Qué es su raza étnica?

Afro Americano

Asiático

Hispano

Islas Pacíficas

Anglo Xahon

6. ¿Cuál es su género sexual?

Masculino

Femenino

7. Cuál es su ingreso anual?

Menos de \$25,000

\$25,000 a \$34,999

\$35,000 a \$49,999

\$50,000 a \$74,999

\$75,000 a \$99,999

\$100,000 a \$149,999

\$150,000 a \$199,999

\$200,000 o mas

8. Cuantas horas trabaja a la semana?

Trabajo 35 horas en la semana o menos

Trabajo 35 horas en la semana o más

No trabajo

Developed by Ida Benavides

APPENDIX C
INSTITUTIONAL REVIEW BOARD APPROVAL

CALIFORNIA STATE UNIVERSITY, SAN BERNARDINO
SCHOOL OF SOCIAL WORK
Institutional Review Board Sub-Committee

Researcher(s): Ida Benavides

Proposal Title: Stress among caregivers of individuals with special needs

SW1779

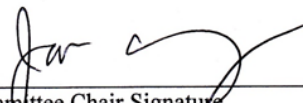
Your proposal has been reviewed by the School of Social Work Sub-Committee of the Institutional Review Board. The decisions and advice of those faculty are given below.

Proposal is:

☒ X approved
☐ to be resubmitted with revisions listed below
☐ to be forwarded to the campus IRB for review

Revisions that must be made before proposal can be approved:

☐ faculty and Investigator signature missing
☐ missing informed consent ☐ debriefing statement
☐ revisions needed in informed consent ☐ debriefing
☐ data collection instruments revision
☐ agency approval letter missing
☐ CITI missing
☐ revisions in design needed (specified below)



Committee Chair Signature

5/24/2017

Date

Distribution: White-Coordinator; Yellow-Supervisor; Pink-Student

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